

# THE REHABILITATION OR HABILITATION OF SEVERELY OR PROFOUNDLY RETARDED PEOPLE\*

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THIS paper will discuss some concepts and procedures involved in the habilitation or rehabilitation of the retarded within three inter-related contexts:

- 1) The number and other characteristics of retarded people in a population of defined size in the United Kingdom.
- 2) The procedures involved in providing services to manage problems arising from the behavior of retarded people.
- 3) The part played by the physician in relation to members of other professions in the provision of such services.

I shall discuss these issues within the conceptual framework of experimental analysis of behavior and the procedures of behavior modification.

First, Becker and others<sup>1</sup> have aptly defined the people to whom I shall refer as "handicapped" or "retarded." I have taken the liberty of substituting "people" where they have used "children:"

*Who are the handicapped?* Handicapped [people] have been given all sorts of labels. Basically, they are [people] who have limitations of sight, hearing, locomotion; [people] who develop slowly and are difficult to teach; [people] who present behavior problems and do things such as head-banging, rocking or using language in unusual ways; [people] who appear to be normal, but do not learn under some teaching methods; and [people] from disadvantaged (often not English-speaking) homes. The people are given various labels, such as deaf, blind,

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or orthopedically handicapped, trainable mentally retarded, educable mentally retarded, autistic, socially maladjusted, perceptually handicapped, brain injured, emotionally disturbed, specific learning disability, and disadvantaged.

For the most part, the labels are not important. They rarely tell the teacher who can be taught in what way. Often one could put five or six labels on the same [person] and still not know what to teach him or how. It is still necessary, in each case, to find out what a person can or cannot do and then teach him what he needs to know. Like [people], "handicapped" [people] learn what they are taught. Sometimes with handicaps such as blindness, deafness, or paralysis, it may be necessary to use different input channels or different response modes in teaching the [person], but the task is still teaching—getting the task responses to occur to the task signals.

*Levels of Retardation.* Retardation is said to exist on the basis of three criteria:

1. *Retarded acquisition of physical skills.* Skills such as crawling, walking, making sounds are acquired more slowly.
2. *Retarded acquisition of social skills.* Skills for playing and interacting with others are acquired more slowly.
3. *Retarded acquisition of intellectual skills.* Concepts and operations are more slowly acquired. Retarded [people] usually show slow development in all three areas. The legal or medical decision to call a [person] retarded often depends on an evaluation of the pattern of the individual's adjustment to his own environment. Can he make it there or must he be taken care of by the State?

The task of the physician or any other professional concerned with mental handicap might usefully be set within the context, first, of the number of retarded children and adults in communities of a defined size and, second, the number of personnel available to deal with them. I shall therefore present some information from the United Kingdom on both categories. I shall assume that the value of any information gained as a result of the efforts of any of the professionals involved might be judged by the extent to which these efforts help in the management of an individual retarded child or adult, including management by himself, his parents, his teachers, or the staff personnel who may

participate in any way in helping to care for him in a residential setting.

Considerable effort may be expended in the detection of etiological factors and in the precise categorization of unusual physiological (organic) variables present in an individual case. However, it is often impossible to detect such variables, and, where it is possible, the organic or physiological variables which are revealed seldom can be manipulated to influence the social or behavioral progress which the person may make. Although this information may be helpful in counseling parents on their risks of having another child with such a handicap, the evidence suggests that the major clinical effort might more usefully be channeled by teams of professionals toward working with members of other disciplines—parents, nurses, and other members of the community—in the development of individual programs oriented toward the habilitation or rehabilitation of the individuals concerned.

A recent book edited by Dr. Margaret Griffiths<sup>2</sup> on the medical aspects of care of the young retarded child illustrates the wide range of diagnostic procedures which may be utilized by medical specialists. The therapeutic responses which can follow the diagnosis are much less evident.

In two excellent papers jointly written by a psychologist and a psychiatrist<sup>3, 4</sup> the need is stressed for developing a diagnostic classification in psychiatry which is both easily comprehensible and specifically related to therapy. These authors suggest that each diagnosis be based on a functional analysis of the problem behavior.

Table I shows the distribution of probable and possible etiological factors associated with severe and mild mental handicap among people identified in the Wessex Survey, between the ages of 15 and 19.<sup>5</sup> Associated etiological factors were identified in only a small proportion of the cases: infection was associated with approximately 4 to 6%, including 0.3% prenatal; toxic prenatal factors accounted for approximately 3 to 5%; metabolic factors were identified in less than 1%; injury (mainly birth trauma) was associated with approximately 10 to 14%, of which only 1% of the cases were identified as reasonably certain of having this cause; and new growth accounted for considerably less than 1%. No known factors are associated with the remaining cases, which constitute more than three quarters of the total. Among these remaining cases, in the severely subnormal (SSN) group—those with intelligence quotients of less than 50—more than one third had Down's

TABLE I. WESSEX SURVEY: ETIOLOGICAL FACTORS AND GRADE OF RETARDATION (AGES 15 TO 19 YEARS)

| <i>Etiological factors</i>     |  | <i>SSN</i><br>(%)  | <i>MSN</i><br>(%)  |
|--------------------------------|--|--------------------|--------------------|
| Infective                      |  |                    |                    |
| Prenatal                       | Maternal rubella                       | 0.3                | 0                  |
|                                | Toxoplasmosis                          | 0                  | 0.4                |
| Postnatal                      | Tuberculous meningitis                 | 0.5                | 0.2                |
|                                | Meningitis: unknown                    | 0.8                | 2.8                |
|                                | Encephalitis: known                    | 0.5                | 0.9                |
|                                | Encephalitis: unknown                  | 0.2                | 0                  |
|                                | Rubella                                | 0                  | 0.2                |
|                                | Possible postnatal                     | 1.3                | 1.3                |
| Total infective                |  | 3.6                | 5.8                |
| Toxic                          |  |                    |                    |
|                                | Kernicterus                            | 0.2                | 0                  |
|                                | Retrolental fibroplasia                | 0.2                | 0                  |
|                                | Postimmunization                       | 0.2                | 0                  |
|                                | Rhesus                                 | 1.0                | 1.1                |
|                                | Jaundice                               | 0.7                | 0                  |
|                                | Other possible toxic                   | 2.6                | 1.9                |
| Total toxic                    |  | 4.9                | 3.0                |
| Injury                         |  |                    |                    |
|                                | Birth injury                           | 1.0                | 0.9                |
|                                | Possible birth injury                  | 12.8               | 9.5                |
| Total injury                   |  | 13.8               | 10.4               |
| Metabolic                      |  |                    |                    |
|                                | Lipoidosis                             | 0.2                | 0                  |
|                                | Hypothyroidism                         | 0.3                | 0.6                |
|                                | Muscular dystrophy                     | 0.2                | 0.2                |
| Total metabolic                |  | 0.7                | 0.8                |
| New growth                     |  |                    |                    |
|                                | Cancer                                 | 0.2                | 0                  |
| Total new growth               |  | 0.2                | 0                  |
| Cause unknown                  |  |                    |                    |
| Perinatal                      | Down's syndrome                        | 27.5               | 3.3                |
| malformation                   | Microcephaly: alone                    | 0.8                | 0                  |
|                                | Microcephaly: with other malformations | 0.3                | 0                  |
|                                | Multiple malformation                  | 4.8                | 4.6                |
|                                | Hydrocephaly                           | 0.8                | 0.2                |
|                                | Other definite diagnoses               | 0.3                | 0                  |
|                                | Diagnosis unknown                      | 0.2                | 0                  |
| All perinatal malformation     |  | 34.7               | 8.1                |
| Neurological signs             |  |                    |                    |
|                                | Motor disturbance                      | 4.4                | 2.4                |
|                                | Epilepsy                               | 7.1                | 7.6                |
| All neurological signs         |  | 11.5               | 10.0               |
| No neurological signs          |  |                    |                    |
|                                | Cultural familial                      | 4.1                | 9.7                |
|                                | Psychotic                              | 1.2                | 0.4                |
|                                | Severe personality disorder            | 0.5                | 2.0                |
|                                | Non-neurological                       | 20.0               | 37.1               |
| All without neurological signs |  | 25.8               | 49.2               |
| No information                 |  | 4.9                | 12.9               |
| Total cause unknown            |  | 76.9               | 80.2               |
| Grand total                    |  | 100.0<br>(N = 608) | 100.0<br>(N = 539) |

SSN = severely subnormal (intelligence quotient of less than 50); MSN = mildly subnormal (intelligence quotient of between 50 and 100).

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TABLE II. WESSEX SURVEY: BEHAVIORAL CATEGORIES AND CLINICAL DIAGNOSES FOR SEVERELY SUBNORMAL SUBJECTS (AGES 15 TO 19 YEARS)

| <i>Diagnosis</i> | <i>Behavioral category (%)</i> |               |           |            | <i>Number known</i> | <i>Total</i> |
|------------------|--------------------------------|---------------|-----------|------------|---------------------|--------------|
|                  | <i>NA</i>                      | <i>All SB</i> | <i>SI</i> | <i>CAN</i> | <i>= 100%</i>       |              |
| NK and other     | 5.9                            | 11.8          | 0         | 82.3       | 17                  | 17           |
| D                | 2.5                            | 6.1           | 0.6       | 90.8       | 163                 | 167          |
| MD               | 28.1                           | 9.4           | 9.4       | 53.1       | 32                  | 32           |
| CP               | 37.7                           | 6.6           | 9.8       | 45.9       | 61                  | 61           |
| MA               | 8.1                            | 16.2          | 8.1       | 67.6       | 37                  | 37           |
| EP               | 2.7                            | 32.9          | 15.1      | 49.3       | 73                  | 74           |
| NBD              | 2.3                            | 14.6          | 5.2       | 77.9       | 213                 | 220          |
| All diagnoses    | 7.9                            | 13.4          | 5.9       | 72.8       | 596                 | 608          |

NA = nonambulant (unable to walk); ALL SB = all severely behavior disordered (able to walk but presenting seriously disruptive behavior); SI = severely incontinent (not in the NA or All SB categories but severely incontinent); CAN = continent, ambulant, and with no severe behavioral disorders; NK and other = not known; D = Down's syndrome; MD = Conditions almost always associated with mental handicap (e.g., phenylketonuria, lipidoses, microcephaly, hydrocephaly, craniostenosis); CP = cerebral palsy; MA = major congenital abnormalities; EP = epilepsy; NBD = no clinical evidence of brain damage.

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syndrome, less than one tenth had other perinatal malformations, approximately one seventh had signs of neurological damage, and approximately one third had no neurological signs. No information was available on approximately one twentieth. The equivalent proportions among the remaining mildly subnormal (MSN) group—those with intelligence quotients of 50 or more—showed that approximately one in 25 had Down's syndrome, approximately one in 20 other perinatal malformation, approximately an eighth had signs of neurological damage, and more than three fifths had no neurological signs. No information was available on approximately a sixth.

Table II shows the relation observed between important social and physical abilities of retarded people and the major associated clinical signs among all severely and profoundly retarded adolescents aged 15 to 19 years. The only significant associations are a higher proportion of nonambulant (NA) people among those with conditions nearly always associated with mental handicap (MD), or with cerebral palsy

TABLE III. WESSEX SURVEY: DISTRIBUTION OF ALL KNOWN RETARDED PEOPLE IN THE UNITED KINGDOM BY AGE GROUP, GRADE OF RETARDATION, PLACE OF CARE, AND SOCIAL OR PHYSICAL INCAPACITY\*

| Age group               | Grade | Place of care | Behavioral category |         |       |         | Total‡  |
|-------------------------|-------|---------------|---------------------|---------|-------|---------|---------|
|                         |       |               | NA†                 | All SB† | SI†   | CAN     |         |
| Children<br>(under 16)  | SSN   | Home          | 4 (1)               | 4 (3)   | 2 (1) | 20 (17) | 30 (22) |
|                         |       | Institution   | 5                   | 5 (2)   | 3 (2) | 5 (4)   | 18 (9)  |
|                         | MSN   | Home          | 1                   | 1 (1)   | 1     | 7 (6)   | 9 (7)   |
|                         |       | Institution   | 0                   | 1       | 0     | 1 (1)   | 2 (2)   |
| Adults<br>(16 or older) | SSN   | Home          | 2 (1)               | 2 (1)   | 1     | 45 (18) | 50 (20) |
|                         |       | Institution   | 6 (1)               | 14 (3)  | 6 (1) | 53 (19) | 80 (24) |
|                         | MSN   | Home          | 1                   | 0       | 0     | 69 (10) | 75 (10) |
|                         |       | Institution   | 2 (1)               | 4 (2)   | 1     | 45 (16) | 53 (18) |

\*Rates per 100,000 total population.

†NA, All SB, and SI are referred to collectively as CAN'T.

‡Includes cases where incapacity is not known.

||Figures in parentheses indicate the number who were receiving formal education or training at the time of the survey.

SSN = severely subnormal (intelligence quotient of less than 50); MSN = mildly subnormal (intelligence quotient of between 50 and 100); NA = nonambulant (unable to walk); All SB = all severely behavior disordered (able to walk but presenting seriously disruptive behavior); SI = severely incontinent (not in the NA or All SB categories but severely incontinent); CAN = continent, ambulant, and with no severe behavioral disorders.

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(CP), and of the severe behavioral disorders (all SB) among the ambulant people with epilepsy (EP). On the other hand, it is clear that by 15 to 19 years of age the great majority are, despite the inadequacies of existing educational and other provisions, continent, ambulant, and have no severe behavioral disorders (CAN). Recent advances in educational methods and expansions in the provision of services,<sup>6</sup> if introduced, could well increase this proportion.

Table III shows, in crude rates per 100,000 of the total population, the distribution of all known retarded people by age group (children and adults), grade of retardation (MSN and SSN), place of care (home or institution), and behavioral category. The figures in parentheses show those who were receiving formal education or training at the time of the Wessex Survey; a large proportion of the retarded adults

TABLE IV. PERSONNEL AVAILABLE TO A POPULATION OF 100,000

|   | <i>Number</i> |
|---|---------------|
| General practitioners                   | 40            |
| Local health authority medical officers | 5             |
| Pediatricians or child psychiatrists    | 1             |
| Physicians                              | 1.8           |
| Psychiatrists                           | 1.5           |
| Educational psychologists               | 1             |
| Social workers                          | 12+           |
| Home help                               | 63+           |
| Health visitors                         | 12+           |
| Home nurses                             | 18+           |
| Teachers                                | 5+            |

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were not receiving any. This data should be viewed in relation to Table IV, which shows the average number of medical and nonmedical personnel in England and Wales available to participate with parents, relatives, neighbors, nurses, houseparents, and teachers in caring for the retarded at home and in residential settings. Any planning of future services must relate the number of clients to the number of people available to help them. Table IV shows that for this total population the key personnel available in any significant number to provide regular counseling and practical help are general practitioners, social workers, home help,\* health visitors, and home nurses. Other specialties, especially consultant psychiatrists for retardates, are now available at the rate of approximately 0.4 per 100,000 total population.

#### PROCEDURES INVOLVED IN "CARING"

I shall now turn to the procedures which my colleagues, Don Horner and Roger Blunden, and I have identified in our research on services for the aged and for people categorized as mentally retarded as being the most important for managing any people with chronic handicaps. These procedures are not mutually exclusive—indeed, it is likely that all people will at some time experience one or more of them. I have noted the relative scarcity of professional people in relation to

\*The English "home help" is roughly equivalent to the American "homemaker."

the size of the commitment required. It seems important, therefore, that professionals ensure that they are using their particular skills with maximum effectiveness—for example, by working as effectively as possible with professionals from other disciplines. Are they wasting their valuable resources by performing tasks which can readily be undertaken by other professional groups? Are they, at considerable cost and hardship to their clients, acting independently of other professional groups or even pursuing conflicting ends? The five procedures which we identified as being most important are:

1) *The identification of organic or physiological variables.* These may account for the behavioral deficits in the handicapped person and, if manipulated, may prevent further deterioration in the individual's behavior and life chances or may even lead to important improvements in function.

This is the clearest function of the physician trained in physiological medicine, working together, where necessary, with colleagues from other relevant disciplines. The obvious example of such a procedure is the detection of an acute organic process which results in a sudden deficit in the function of the individual and may also produce excesses of operant or respondent behavior such as complaining, overbreathing, or diarrhea. The detection of the responsible organic variable can result in drug therapy which dramatically will remove the excesses of behavior and restore appropriate function. There are other conditions, of course, in which the effects of treatment are less dramatic and where the treatment may take longer. However, the process here is essentially the manipulation of physiological variables with a fairly precise technology which can be easily monitored. Some of these procedures are technically feasible at home, for example, the exhibition of powerful drugs and antibiotics. Others must be undertaken in places which have extensive technological resources and require careful monitoring by specialists.

We do not believe that the detection of organic or physiological variables which *cannot* at present be manipulated to affect the patient's life chances or behavior should have a high priority. Although such investigations may be necessary as part of research programs designed to answer specific questions, caution might well be observed in the unnecessary investigation and detection of organic variables which *cannot* be manipulated. This caution extends especially to the identification



of syndromes merely to satisfy the curiosity of the investigator.

By this criterion, any screening programs for physiological variables would be directed toward the detection of those organic variables which can be manipulated with benefit to the individual concerned or to his patients. An obvious example of this would be the detection of phenylketonuria or galactosemia. I shall return to the consideration of some other relevant physiological variables further on.

2) *Rehabilitation or habilitation.* This includes procedures undertaken with the aim of increasing the frequency or consistency of socially appropriate responses (such as walking, self-feeding, washing, dressing, relating socially, attending, reading, writing, counting, solving problems, etc.) or of decreasing the frequency and amplitude of "inappropriate" behavior such as self-injury (head banging, for example), injuring other people, and other forms of socially disruptive behavior (e.g., smearing feces).

Where possible, "inappropriate" behavior is decreased in frequency and amplitude when replaced by incompatible, appropriate behavior. Procedures are also available which set the occasions in which appropriate responses may take place, which shape these responses into new and more complex activities by differential reinforcement and which ensure that the consequences to the handicapped person of these activities will motivate him to maintain or develop the activities. These procedures are most effective when they limit the opportunities for inappropriate behavior and ensure that when such behavior does occur the consequences do not motivate its repetition.

Handicapped people may, like anyone else, become more incapacitated as a result of organic processes; these can often be dealt with quickly by providing access to appropriate facilities for treatment. However, after the acute organic process is dealt with, the original deficits remain and the procedures of rehabilitation or habilitation therefore should again receive the highest priority.

With respect to important behavior such as learning to walk; to feed, wash, and dress oneself; to talk; to play; and to relate to other people—the key people involved in both setting the occasions for these activities and encouraging or reinforcing them when they occur are, of course, the parents and relatives of the handicapped individuals. For those handicapped people who are unable to stay at home or live independently the key personnel are the nurses or houseparents in the

residential settings and educators. It is important to recognize that, however well informed are the professionals in any therapeutic setting, they cannot themselves set the occasions for the many subtle activities in which handicapped people must learn to function: for activities which must be reinforced immediately after they take place if they are to be maintained or increased in frequency and amplitude.

Professionals, therefore, should advise planners on appropriate designs for residential or day-care facilities. They should also take part—together with parents, nurses, teachers, and others—in the development of individual habilitation or rehabilitation programs for handicapped persons. Where organic or physiological variables are detectable and are likely to influence the responses of individuals, the specialists in these fields should act as consultants and teachers to the people delivering the care to the handicapped. Similarly, these specialists can, after investigation, eliminate organic variables as causes of changes in behavior and reassure clients, relatives, and others that other causes and solutions must be found.

3) *The provision of a prosthetic environment for the handicapped person.*<sup>7</sup> A prosthesis compensates for certain deficits of behavior or experience of the individual and allows him or her a wider range of successfully emitted responses. For example, spectacles, hearing aids, walking aids, and various orthopedic appliances, if appropriately prescribed and if used by the person, allow the individual to make responses to visual or auditory stimuli to which he would not otherwise respond. Other physical prostheses—such as wheel chairs which are not self-propelled—enable other people to move handicapped individuals around. Their presence does not increase the motor responses of the handicapped person but may increase his social responses.

Cosmetic prostheses such as wigs, false eye-lashes, and false teeth may enable the handicapped person to enter into social relations with others more easily. The people on whom the handicapped person is dependent may be put off by his appearance or may feel embarrassed when relating with others in the presence of the handicapped person.\*

Under the heading of prostheses it is also useful to include social prostheses: that is, the provision of additional individuals who perform

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\*The residents of facilities for the handicapped often appear very different from "normals" because they are deprived of false-teeth, make-up, and foundation garments; have outmoded haircuts; and wear ill-fitting, poorly maintained, or unfashionable clothing.

necessary functions for the handicapped person which he or she is unable to perform; for example, someone might feed, bathe, clean house for, cook for, or shop for him. This may make it unnecessary for the handicapped person to develop these skills himself. While such procedures are, of course, very effective, it is important to recognize that they will *not* increase the frequency, amplitude, or consistency of the handicapped person's responses in the way that an effective rehabilitation or habilitation program would. It is also possible that the provision of both physical and social prostheses may actually, unintentionally, discourage the development or maintenance of socially appropriate behavior. This may have the effect of providing time in which the person—unless able to undertake other creative activities—might engage in socially disruptive behavior.

Conversely, the availability of more elaborate environmental prostheses such as electronically controlled doors, typewriters, and other devices could have the effect of substantially increasing the range of activities of handicapped people. However, subtle features of buildings and sidewalks designed for "normal" people can unintentionally but seriously limit the possible activities of "handicapped" people.

These measures are often simply *not* undertaken; when they are undertaken they may *not* succeed in developing and maintaining appropriate behavior or in preventing the development of inappropriate behavior which disrupts the other members of the social groups with whom the handicapped people live. Other procedures then come into operation.

4) *Procedures which have the effect of mechanical or chemical restraint, incarceration, or punishment.* Mechanical or chemical-restraint procedures decrease the possibility of *all* behavior, both appropriate and inappropriate. The effect of incarceration is that the handicapped person, although he is not physically or chemically restrained, is confined to a limited area which he cannot leave except under extremely restricted conditions. Practices which are called punitive are employed where inappropriate behavior is followed by *unconditioned* physical or other stimuli which weaken the person's behavior. Alternatively, threats (conditioned stimuli) are employed; as long as inappropriate behavior is not expressed, punishment is avoided.

Techniques having the effects of restraint, incarceration, and punishment are used and will continue to be used so long as it is not pos-

sible to use practices which replace inappropriate behavior with a wide range of rich and socially appropriate activities. The procedures of manipulation of physiological variables have little place where there is no evidence that these influence behavior. Therefore, the major procedures available are techniques with rehabilitative or prosthetic effects. Indeed, a sensitive measure of the quality of care given to handicapped people may well relate to the proportion of people for whom, at any time, it is necessary to employ techniques which are effective through controls such as restraint, incarceration, and punishment.

Drugs or psychosurgery under some circumstances have the effect of a form of chemical restraint while in other circumstances they have the effect of procedures which manipulate physiological variables and which expand the range of socially appropriate behavior. It should become increasingly possible to differentiate the use of drugs which have the effect of increasing the range of appropriate behavior from procedures which appear similar but have the effect of restraining the person's behavior. The chemical restraint of behavior is characterized by a reduction of the frequency and amplitude of *all* actions, both appropriate and inappropriate. The positive use of drugs and psychosurgery will selectively have the effect of expanding the range of appropriate behavior while decreasing the frequency and amplitude of inappropriate behavior.

#### IMPLICATIONS FOR SERVICE PROVISION

First, the medical personnel caring for retarded people in all locations should neglect no opportunity to detect physiological variables which could be manipulated to expand an individual's range of behavior. Where this fails, medical personnel must join with people from a wide range of disciplines involved in rehabilitation or habilitation procedures or the provision of prosthetic devices, particularly those which are likely to expand the range of appropriate behavior.

Rapid advances are being made in the conceptualisation and development of rehabilitation and prosthetic procedures. These arise from the work of Skinner,<sup>8</sup> Lindsley,<sup>7</sup> and Bijou<sup>9</sup> on the functional analysis of behavior and its application to teaching methods through the techniques of behavior modification, precision teaching, and operant conditioning. These techniques are used not only by psychologists<sup>9-13</sup> but also by educators,<sup>1, 14</sup> social workers,<sup>15, 16, 17</sup> and psychiatrists.<sup>3, 4, 18</sup>

We are now aware that handicapped people, of whom it had been confidently predicted by concerned professionals that they were incapable of acquiring skills, have acquired a wide range of skills which have given them a greater control over their environment and relieved others of many aspects of their care. The new techniques and concepts have helped to develop procedures which effectively build on existing behavioral repertoires. It is fundamental to this approach that where these techniques fail the responsibility is laid clearly on the teacher or rehabilitator, who must then devise a new program. This new approach views any diagnosis which implies that an individual is neither capable of responding to ordinary stimuli nor of acquiring new responses as merely an avoidance behavior on the part of the diagnostician.

Many difficulties arise in redirecting service personnel toward a habilitative or rehabilitative approach. The first problem is achieving collaboration between groups of professionals. The physician would of course be a member of such a group. Physicians and many of the professionals concerned will have to acquire new skills if they are to implement these new procedures together. Laurence Weed, who has made a major contribution to the guiding and monitoring of medical practices through the design of a medical record in which problems are identified and procedures are planned and documented to solve these problems, says:<sup>19</sup>

1) Physicians have never been assigned a definite population for which they are responsible. Patients entered the physician's care at random, often for symptomatic treatment, did not remain a stable population even then, often were not, or could not, be followed up, and rarely were the subjects of the practice of the true preventive medicine.

2) Influenced perhaps by the randomness of their patient populations, physicians have kept incomplete data and have randomly recorded what data they have obtained without clearly associating each element of information with a well-defined problem.

B. I. Liskow, in a letter to the *British Journal of Psychiatry*,<sup>20</sup> refers particularly to the problem of keeping psychiatric records:

As long as the psychiatrist keeps in mind that the ultimate goal of problem-oriented medical records is the integration of a patient's various medical, emotional and social problems in a

way that is comprehensible to all those who must deal with the patient . . . he will regard himself as a necessary part of a system working to provide the patient with comprehensive, complete and intelligent medical care. To operate otherwise would be to isolate psychiatry further from medicine to the ultimate detriment of medicine, psychiatry and the patient.

A second difficulty arises from a lack of skills and knowledge among medical and other professionals of the variables which maintain operant or instrumental behavior, of the procedures for teaching new skills, and of the wide range of programs now available for teachers, nurses, and the families of the retarded.

Larsen and Bricker's manual<sup>21</sup> has been widely used in the United States and is now being used in England. In England the Hester Adrian Research Centre in Manchester and the National Society for Mentally Handicapped Children (North West Region) have produced an excellent first publication designed for use in a workshop with parents.<sup>22</sup> There are now many more programs for teaching specific skills. An important recent contribution is that by Foxx and Azrin<sup>13</sup> on rapid procedures for toilet training. Further, texts are also available for parents, teachers, and other professionals.<sup>23-25</sup>

The task of setting up multidisciplinary community teams to deliver rehabilitative and prosthetic services to the mentally handicapped in all situations is now probably the most important challenge. The medical contribution to this work could take place at many levels: in hospitals within the specialist services, in general practice outside of hospitals, and through the services of community psychiatrists and physicians. Because of the large target population involved and the small number of professionals available, this exercise can succeed only if the contribution of the medical personnel lies mainly in their capacity as consultants and advisors to the teams of more numerous people who will deliver the services directly to the clients.

#### PROBLEMS ARISING FROM POOR FACILITIES WHICH ARE OFTEN ALSO INCONVENIENTLY SITUATED

It is unwise and frustrating to attempt to implement major changes in an individual's performance unless the settings in which that performance takes place give positive support to the widest range of so-

cially appropriate behavior. Existing residential wards in hospital environments often fail to provide the settings for most of the subtle and delicate socially communicative responses which are part of everyday life. Indeed, they often fail to set the occasions for such basic activities as independent walking, toilet use, feeding, washing, and dressing. They often inadvertently ignore or even punish these appropriate responses while reinforcing inappropriate, aggressive, or disruptive behavior for which patients always receive staff attention. Dependent or compliant behavior is also maintained by noncontingent staff reinforcement.

I have described elsewhere <sup>26</sup> the manner in which the large catchment areas served by existing hospitals—rather than small geographical areas served by small industrial units which would be closer to the families of the residents—does not foster and, indeed, obstructs attempts to achieve continuing habilitation programs for mentally handicapped people at home as well as in residential care. In England we have found that the logistics problems inherent in attempting to coordinate the relevant activities become very complex indeed when the number of professionals involved rises much above those serving a population of 100,000.

#### TOWARD MEASURES OF QUALITY OF CARE

I do not share the alarm expressed by some writers in the United States and in England at the development of concepts or procedures which arise from the experimental analysis of behavior and from attempting to modify behavior by operant conditioning. I do, however, share the concern expressed by others at the powerful contingencies which control the behavior of all members of industrial societies because we are either unaware of them or are unable to predict the short- and long-term effects of changing them. By attempting to make explicit the changes in behavior which we are aiming for and the procedures by which we hope to achieve them and by then monitoring the extent to which the measures succeed we might achieve greater freedom from a spurious control by variables and some counter-control over the many practices which are not explicit.

Applied to the delivery and evaluation of health, education, and welfare services, these concepts should prove useful for focusing on specific observable responses of individuals in various settings—identify-

ing and predicting which variables in the social or physical environment appear to be controlling that behavior in those settings and testing these predictions empirically by manipulating the variables and observing changes in behavior.

As concepts and procedures are developed to take account of subtle or symbolic variables in the environment, these should become more effective. This should enable us to avoid the use of, first, physical and chemical procedures which have the obvious effects of punishment and restraint; later we should be able to avoid the more subtle punishing effects used in controlling the behavior of the mentally retarded and of those of us who work with them.

My colleagues and I are working on a method of measuring the quality of residential care which develops within this framework.<sup>26</sup> Briefly, we have distinguished high-quality care from low-quality care in that clients receiving the former are more likely to: 1) have many opportunities for successfully undertaking a wide range of responses in a variety of settings, 2) receive social reinforcement (e.g., praise, attention, and contact with staff in all settings contingent on socially acceptable responses, and 3) continue over time to maintain or acquire more response opportunities and responses. People receiving low-quality care will be more likely to: 1) have a smaller range and number of opportunities for appropriate responses, 2) receive less social reinforcement for any acceptable behavior in those settings in which opportunities for it are provided, and 3) have decreasing opportunities for appropriate responses as well as a decreasing number of these responses. In this formulation, high-quality care, as compared with low-quality care, also would be characterized by 4) a smaller proportion of socially inappropriate behavior being reinforced by staff responses (i.e., staff would selectively ignore such responses), and 5) a lower proportion of staff responses during a shorter period of the lives of individuals having the effect of chemical or physical restraint or incarceration which deprive the retarded individual of a wide range of opportunities for appropriate responses.

If successful, we should be able to quantify these differences in the quality of care provided for the retarded. As the severely retarded persons themselves are powerless to determine the quality of their environment, others have to do it on their behalf. At present, those who care for the retarded often react intuitively to a wide range of com-



TABLE V. SOCIAL INCAPACITIES AND PLACE OF RESIDENCE FOR THE ELDERLY AND MENTALLY HANDICAPPED MEMBERS OF A TOTAL POPULATION OF 100,000

| <i>Elderly (aged 65+ years)</i> |                | <i>Mentally handicapped (all ages)*</i> |                |
|---------------------------------|----------------|---|----------------|
| <i>Incapacity</i>               | <i>Number†</i> | <i>Incapacity</i>                       | <i>Number†</i> |
| Bedridden                       | 350 (220)      | Nonambulant                             | 21 (8)         |
| Confined to home                | 1,410 (1,300)  | Severe behavioral problems              | 31 (7)         |
| Mobile outdoors with difficulty | 1,020 (910)    | Severely incontinent                    | 14 (4)         |
| None of the above               | 9,240 (9,100)  | None of the above                       | 247 (142)      |

\*Includes both severely and mildly subnormal persons (intelligence quotients of less than 100). Source: Wessex Survey.

†Figures in parentheses indicate those who were living at home.

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ponents in these settings (decor, clothing, smiles of the residents, and other less easily observable features of the setting). The retarded who under the existing methods of control, are disruptive in reasonably pleasant settings offering a wide range of opportunities are transferred to settings to which they are restricted, in which fewer such opportunities exist, and where cruder methods of control are used.

#### THE MENTALLY RETARDED AND OTHERS WITH CHRONIC HANDICAP

Table V compares the prevalence and nature of the handicaps of people who are labelled "mentally retarded" with the same data for handicaps among the elderly in a total population of 100,000. Two points arise from the data in this table:

1) Compared with the number of elderly people with severe behavioral deficits, the number of profoundly or severely retarded people to whom services might be delivered is relatively small. In England and Wales, where the elderly constitute only 12 or 13% of the total population, they account for approximately 40% of the patients in psychiatric and 42% of those in nonpsychiatric hospitals.

2) The role played by medical specialists in providing services for people with severe or profound retardation constitutes only a small portion of the role they will be required to play in helping people with any sort of chronic handicap. The relevance of this problem to the work

and training of medical, educational, and social practitioners and researchers is only now beginning to be generally recognized.

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